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## Importance of Family Engagement in Community Groups

**Diane Perry**, a PEAL Parent Advisor, was recently named Chairperson of the Special Education Advisory Panel (SEAP). This panel works to improve special education in Pennsylvania and serves in an advisory capacity for the PA Department of Education's Bureau of Special Education and the Office of Child Development and Early Learning. Federal special education regulations require that each state establish an advisory panel whose members include representatives from specific stakeholder groups, including families. The contributions of Diane and other family members on SEAP has been key in ensuring that the family vision of inclusiveness and presumed competence of students with disabilities is continually present as issues are considered and advice is provided.



SEAP is just one example of decision-making groups that families, youth and self-advocates can participate in at the local and state level. PEAL team members and other families participate in groups including: Local Task Force on the Right to Education (LTF) in every Intermediate Unit region, Local Interagency Coordinating Councils (LICC), State Interagency Coordinating Council (SICC), and others to make sure that we have a voice when decisions are made that affect people with disabilities in our communities.

Sharing insights that your family has experienced while living with a disability, and/or special health care needs is a powerful tool to influence decision-making. Many boards and groups have a requirement to include family members and individuals who are self-advocates because first-hand experiences with the impact of programs and services are critical perspectives. Some families join a group because they have seen a need for a change in how the "systems" operate, while others join as an opportunity to learn how decisions are made and connect with other families.

*"While I may not have been personally touched by every injustice, I felt it was important to join, not only for the disability community, but also to give back and continue to break down barriers as families had done before me."*  
Diane Perry, Parent Advisor, PEAL Center

In addition to influencing positive outcomes for people with disabilities, membership to groups and committees provides other benefits. Families can often feel alone while they navigate the special education or health care systems; there can be "us vs. them" mentalities that can make you feel isolated. However, by joining these groups you can connect with other families who have shared experiences.

If you are interested in joining a group, here are a few ways to start:

- ✓ Join local support groups in your area
- ✓ Attend a Local Task Force meeting at your regional Intermediate Unit
- ✓ Sign up for newsletters from organizations that support people with disabilities
- ✓ Join and follow Facebook groups

### Special Education Resources for Families:



This new publication describes organizations that assist families, including those whose primary language is not English.

English: [bit.ly/2oMjRFX](http://bit.ly/2oMjRFX)  
Spanish: [bit.ly/2CeCqfn](http://bit.ly/2CeCqfn)

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→ SEAP: <http://www.pattan.net/category/About/Partners/Single/?id=14>.

→ For more information about ways to bring your family voice to decision-making groups in your area, contact PEAL [info@pealcenter.org](mailto:info@pealcenter.org) or call us.

# The Importance of Getting Involved

This article was written by Linda Carmona-Bell and appeared in the [FAMILIES TO THE MAX Summer 2018 Newsletter](#).



Linda Carmona-Bell

We as parents and guardians of children with disabilities hear constant appeals to get involved in groups and committees. We hear that more family participation is needed to give a family perspective. But who wants to speak in front of people? Who wants others to dive into their personal business? Let's face it . . . **Who has time?**

You do! When it comes to your family members having a better quality of life YOU HAVE TIME. Use your time effectively to find out things that you never knew before that could make your everyday life easier. Sometimes it is just giving your valuable opinion to a project that will impact thousands of individuals, including your family. Sometimes, it is using one hour of one day in a meeting to learn things that that will increase your families quality of life.

## Involvement at School

When we hear "family involvement" in a school setting, it can mean showing up for a meeting, asking questions about grades or the topic being studied, or many other things. When we participate in meetings such as our child's IEP or 504, we become our child's voice— their advocate—the person who is representing their needs. Research shows that family involvement absolutely increases student achievements for all students.

## Involvement in the Community

Family involvement in community activities that affect your family member with disabilities has many forms. It may be:

- Attending a meeting in your local area to learn new things
- Asking questions about policies, decisions, or new programs
- Providing your opinion to a committee so that your specific concerns can be considered



It can mean so much more! No matter how you look at it, the benefits of being involved are worth it!

## My Experience with Involvement

I started getting involved when my 17 year-old was 4 years old. I have not stopped. I have learned more from other family members and by attending meetings at local and state levels than I would have ever learned from the school district. I have shared things I know with families. Better yet, the things I've learned have benefitted my child in school, work, and play by providing options that she would have never known. Isn't it worth a try? I think so.

## Where to Begin

Start small with a local group, or join the **FAMILIES TO THE MAX: Statewide Family Network**. Its mission is: **Leading change for children with diverse needs by maximizing opportunities in the home, classroom, and community.**

The network's vision is to empower students, families, and communities to believe that all children can reach their maximum potential. Doesn't this sound awesome? If I were a betting person, I would bet that by taking the step to be more involved in speaking up for your child, doors will open that you never knew were closed! You will be glad you took that first step!

FAMILIES TO THE MAX is a partnership among the PEAL Center, Hispanos Unidos para Niños Excepcionales (HUNE) and PA Training and Technical Assistance Network (PaTTAN). For more information, contact:

- Lorie or Tammi at 1-866-950-1040 (PEAL) or
- Diana at a la Línea de Asistencia del Proyecto MAX (215) 595-5866 (Español e Inglés) (HUNE)
- the Parent Partners, email [parentnetwork@pattan.net](mailto:parentnetwork@pattan.net) (PaTTAN)

Visit the **PEAL Center website to learn more about FAMILIES TO THE MAX:**  
<https://pealcenter.org/families-to-the-max-pennsylvania-statewide-family-network/>.



# When Is a Threat a Threat?

## *The Rights of Students with Disabilities in Schools*

With the increase in incidents of school violence across the United States, school districts are becoming increasingly vigilant in responding to threats. There are no clear criteria for determining whether or not a statement or behavior by a student with a disability in school is considered to be a threat. It is important not to get caught up in the world of threats, but rather to think about each student as an individual and evaluate the specific situation in light of the student's disability.

### *When is a threat real?*



A school is responsible for creating a safe and effective learning environment for all students. However, when a statement or behavior is perceived as a threat by teachers and administrators, it often results in school discipline that excludes the student from school (e.g., suspends or expels the student). Schools are generally limited to disciplining students for activities, including threats, that take place **in school** or coming **to and from school**. In recent years, the judicial system has allowed schools to discipline students for statements and behavior that occurred outside of school (e.g., online: Facebook, Twitter, Snapchat, Instagram, etc.) when it directly affects the school environment.

School officials cannot stop students, including students with disabilities, from posting on social media sites, like Facebook,

when they are outside of school, but there are exceptions. The school can discipline a student for statements made outside of the school day when they can show that the statement:

- Disrupts the school environment
- Makes an explicit threat against a teacher or another student
- Amounts to severe harassment

Refer to the [ACLU PA Handbook: Know Your Rights](https://www.aclupa.org/files/7214/9641/5240/Students_Rights_Handbook_2017_Update.pdf) for further examples and information ([https://www.aclupa.org/files/7214/9641/5240/Students\\_Rights\\_Handbook\\_2017\\_Update.pdf](https://www.aclupa.org/files/7214/9641/5240/Students_Rights_Handbook_2017_Update.pdf)).

### *How should families respond?*

If the school contacts a family about disciplining a child with a disability for making a threat:

- Schedule a meeting with the school administrator as soon as possible.
- Ask to include as many IEP Team members as possible—having an IEP meeting is preferred, but there is not always time.
- At the meeting, it is important to take into consideration:
  - the context of the “threat”
  - the age of the student
  - any previous disciplinary history
  - the expression of the student’s disability, and
  - other factors to determine whether the student’s words or behavior are a real threat to student or school safety, or a manifestation of the students’ disability.

#### Helpful questions to consider while working with the school to determine if a perceived threat is a threat that should be disciplined:

- Is this the first time the student has made this “threat”?
- Is it harassment?
- Is this a real threat?
- Is it an explicit threat against a specific person?
- Will it disrupt the school environment?
- Could the impact of the child’s disability be a factor?
- What is a developmentally appropriate response in light of the disability and the circumstances of the “threat”?
- Has this behavior been addressed in the IEP?

## Are there different rules for students with disabilities accused of making “threats”?

The disciplinary rules or code of conduct at school generally apply to all students, including those with disabilities. A child with a disability is entitled to all of the same school discipline protections as other students. For additional information, refer to the Education Law Center’s publication *Fairness in School Discipline in Pennsylvania* ([https://www.elc-pa.org/wp-content/uploads/2013/08/ELC\\_Guide\\_FairnessinDiscipline\\_Sept09.pdf](https://www.elc-pa.org/wp-content/uploads/2013/08/ELC_Guide_FairnessinDiscipline_Sept09.pdf).)

Special Education regulations provide students with disabilities with additional rights related to school discipline. Most important is the right to a “manifestation determination,” which determines if the student’s behavior was in any way linked to his or her disability, or if the threat was a result of the school’s failure to implement the student’s IEP.

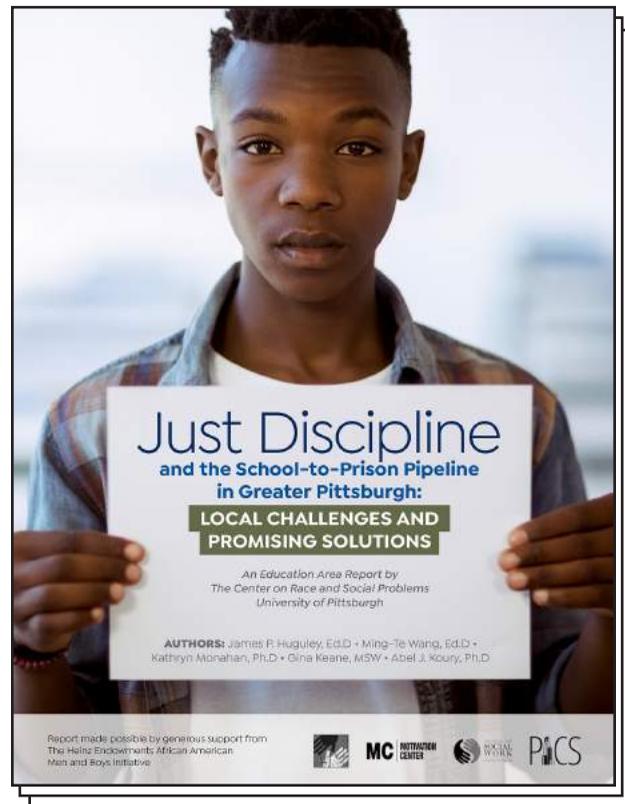
Schools are required to complete a “manifestation determination” if the school is considering suspending a student with a disability for **more than 10 days**. In PA, if a student has an **intellectual disability**, ANY suspension requires a manifestation determination. PaTTAN provides a manifestation determination worksheet that is a helpful tool for IEP teams ([https://pealcenter.org/wp-content/uploads/2018/08/Manif\\_DetermWksht0618-1.pdf](https://pealcenter.org/wp-content/uploads/2018/08/Manif_DetermWksht0618-1.pdf)).

### What is Manifestation Determination?

A formal process to review all information to determine if the student’s behavior (i.e., threat) is linked to his/her disability or failure to implement the IEP.

See <https://www.parentcenterhub.org/manifestation/>

The IEP team makes a manifestation determination which results in a decision about how best to respond to the student’s “threat.” For example, the IEP team may decide that instead of a 10-day suspension, the student needs instruction on the appropriate use of social media.



Despite their wide-spread use, disciplinary exclusions are largely ineffective in reducing problem behaviors. Research shows that the rate of students who have been suspended on multiple occasions ranges between 35 and 42 percent of all students. This suggests that suspensions do not serve as a deterrent for misbehavior. In fact, suspensions may reinforce the use of problem behaviors for students who wish to escape or avoid school. Many school administrators use exclusionary disciplinary measures not because they wish to remove students from the opportunities to learn, but because they need to do something, and they don’t know what else to do (Skiba & Sprague, 2008).

When thinking about school safety, it is also important to note that students with disabilities, and particularly students with disabilities of color, are disciplined at much higher rates for the same behavior as their non-disabled peers. This disproportionate impact of school discipline on students with disabilities is a critical issue for disability advocates across the state. See the 40-page report, *Just Discipline and the School to Prison Pipeline in Pittsburgh*, available at [http://crsp.pitt.edu/sites/default/files/Just\\_Discipline\\_and\\_the\\_School\\_to\\_Prison\\_Pipeline\\_in\\_Pittsburgh\\_1.pdf](http://crsp.pitt.edu/sites/default/files/Just_Discipline_and_the_School_to_Prison_Pipeline_in_Pittsburgh_1.pdf).

Contact the PEAL Center if you have questions or concerns about disciplinary actions of schools for students with disabilities.

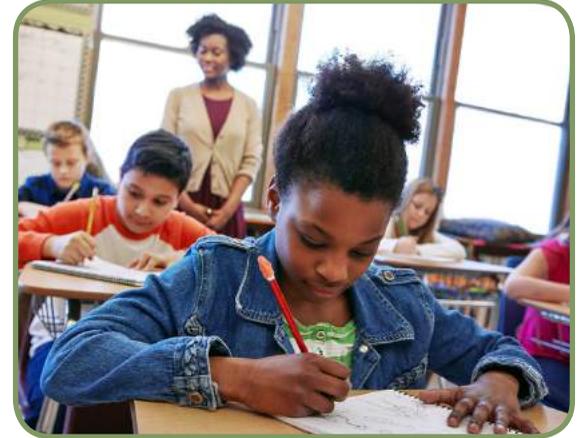


Thank you to our partners from Education Law Center PA for sharing resources for this article.

# Pennsylvania Alternate System of Assessment (PASA): Important Information for Families

PSSA and Keystone tests may be familiar to most parents because most students, including students with disabilities, participate in these statewide assessments. It is also important for families of students with disabilities to be aware of another statewide assessment, the **Pennsylvania Alternate System of Assessment (PASA)**.

***It is critical that parents/guardians are meaningfully involved in the IEP team discussion when a decision is made about whether the student should take the PASA.***



## Which students should take the PASA?

The PASA is an alternate statewide assessment designed for students described as having the “most significant cognitive disabilities.” Students who take the PASA should be those who are **unable** to participate meaningfully in the PSSA or Keystone Exams, even with accommodations.

The IEP team decides each year if a student is eligible to take the PASA. Parents/guardians participate in this decision-making so it is important to understand the guidelines for making the decision so that they are making an **informed decision**.

This is an important decision—the IEP team is required to provide a written explanation of the reasons why:

- the student cannot participate in the PSSA, and
- the PASA is an appropriate assessment for the student.

On the IEP form, the information about assessment is documented in Section IV. Participation in State and Local Assessments:

**IV. PARTICIPATION IN STATE AND LOCAL ASSESSMENTS**  
**Instructions for IEP Teams:**  
 Please select the appropriate assessment option. Information on available testing accommodations may be found in the Accommodations Guidelines available on [www.education.state.pa.us](http://www.education.state.pa.us).

**PASA** (Administered in grades 3-8, 11 for Reading and Math; Grades 4, 8, 11 for Science)

Student will participate in the PASA.

Explain why the student cannot participate in the PSSA or the Keystone Exam for Reading/Literature, Math/Algebra 1, Science/Biology, and Composition (The Composition exam will be available for the 2016-17 school year):

Explain why the PASA is appropriate:

Choose how the student’s performance on the PASA will be documented.

Videotape (preferred method)

Written narrative notes (requires prior approval in accordance with PDE guidance)

In order to decide if the PASA is the appropriate statewide assessment for a student, the IEP team should discuss six (6) questions and decide whether it applies to the student. Prior to the next IEP meeting, parents/guardians may want to review these questions and consider your answers in order to be prepared to be informed decision-makers.

## PASA Eligibility Criteria for IEP Teams

IEP teams must answer “yes” to all six of these questions in order for the student to be eligible to take the PASA. A brief annotation that may provide additional information for consideration is included.

- 1. First Criteria:** “By September 1 of the school year in which this IEP will be operative, will the student be in grade 3, 4, 5, 6, 7, 8, or 11?”  
→ This question is actually for any student who is taking state standardized assessments.
- 2. Second Criteria:** “Does the student have significant cognitive disabilities?”  
→ Consider whether a student has a “significant cognitive disability;” Having a significant cognitive disability is determined by a holistic understanding of a student, NOT by an IQ test score or a disability category (e.g. intellectual disability, learning disability, etc.)
- 3. Third Criteria:** “Does the student require intensive instruction to learn?”  
→ Consider the instructional needs of the individual student as compared to other students who receive special education.
- 4. Fourth Criteria:** “Does the student require extensive adaptation and support in order to perform and/or participate meaningfully and productively in the everyday life activities of integrated school, home, community, and work environments?”  
→ Note the phrase “extensive adaptation and support.” Many students who receive special education services have work that is adapted and supported, but it is not all “extensive.”
- 5. Fifth Criteria:** “Does the student require substantial modifications of the general education curriculum?”  
→ Consider the word “substantial” in light of other students whose instruction may be adapted and modified.
- 6. Sixth Criteria:** “Does the student’s participation in the general education curriculum differ substantially in form and/or substance from that of most other students (i.e., different objectives, materials, or activities)?”  
→ Consider differences in the instruction and content that the individual student receives compared to that of most other students who receive special education.

The IEP team should not take the decision to have the student take the PASA lightly. This decision needs to be thoughtful and must consider the needs and abilities of the student. *The PEAL Center can provide individual assistance to a family to support their understanding of this decision.*

Note: Per PA School Code, a parent can opt their child out of the state assessment if they feel the assessment conflicts with their religious beliefs. However, this not an IEP team decision. If a parent feels the state assessment conflicts with their religious beliefs, they must follow the process for religious exemption with their school district officials. In cases of religious exemptions, the IEP team still addresses the state assessment section of the IEP.

For additional information, you can visit Pennsylvania Department of Education website at [https://www.education.pa.gov/K-12/Assessment and Accountability/Pages/PASA.aspx](https://www.education.pa.gov/K-12/Assessment%20and%20Accountability/Pages/PASA.aspx) or <https://www.pasadigital.com/>.





## SELF-ADVOCACY

—with PEAL's Youth Leadership Coordinator

### youth corner

So how does one come to being a self-advocate? Meet Katie Smith, PEAL's Youth Leadership Coordinator who coaches youth and young adults towards becoming their own best advocate and live the lives that they create for themselves. *Here's Katie's story . . .*



Katie Smith, PEAL's Youth Leadership Coordinator, and Evelyn McConnell, Youth Leader

*Hey there! I'm Katie Smith, I work with youth and young adults to help them develop self-advocacy and leadership skills in order to successfully transition into adulthood.*

*My personal experiences have helped me in this work. I have a physical disability and had to learn how to advocate for myself, especially when it came my healthcare and education. To be honest, it was not an easy journey, but I had guidance and community.*

*Where my story begins, at the age of 21, I was active and engaged in my community and sports. As a senior in nursing school I was ready to transition into my career and next chapters. That summer I was in a car accident, broke my neck and acquired a spinal cord injury that paralyzed me from the chest down. All of a sudden I was in a body that did not work the way that it used to and did not feel like mine. I had to re-learn how to do everything from dressing and feeding myself to getting around in a wheelchair. It was a huge challenge for my family and me to go through. Instead of just letting things happen to me I decided to take control of my own life! I gained self-awareness—an understanding of my unique needs and supports and found a way to communicate them. I became a self-advocate and regained the independence I had*

*felt before having a disability.*

*As I took control of my own outcomes, I decided to return to college to become a teacher. This was a change to my original goal of being a nurse, but this choice felt right for me. I graduated from Seton Hill University as a certified elementary and special education teacher, with a degree in psychology. Along the way, I did not forget my love of sports and community engagement. I found different ways to competitively engage and be active including wheelchair rugby, handcycling, adaptive horseback riding, and boccia. I love to cook and garden—I do it all differently than I did before and need support, but I can still do it! **I could not have gotten to this point without becoming self-aware and a self-advocate—knowing what I need and how to get it.** It was hard work, but worth every challenge that I faced and overcame to feel empowered and have ownership of my life and my choices!*

## KATIE'S TIPS

### WHY SELF-ADVOCACY?

- Ownership of your choices, goals, and outcomes
- Personal understanding of your unique needs
- Build confidence in your skills and abilities
- Solve challenges that others – even caregivers – may not realize
- Develop independence and be empowered!

### STEPS TO SELF-ADVOCACY

- Become self-aware
- Understand your needs and supports
- Make it happen – communicate your needs to others



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## PEAL WEBINARS

PEAL monthly webinars address a variety of topics to provide valuable information to families, youth, young adults, and the professionals who work with them. Webinars range from 30-60 minutes and can be viewed live or streamed for future viewing.

**2018-19 webinars will cover the following topics:**

- Voting
- Extended School Year (ESY)
- Early Periodic Screening Diagnosis and Treatment (EPSDT)
- Healthcare
- IEP Considerations
- 504 Plans
- Transition to Adulthood
- Building Healthy Relationships
- Enrollment Brokers
- Community Health Choices

Dates and times and registration information will be posted at [www.pealcenter.org](http://www.pealcenter.org).

